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# Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008



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# Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008

Autism and Developmental Disabilities Monitoring Network Surveillance Year 2008 Principal Investigators

#### **Abstract**

**Problem/Condition:** Autism spectrum disorders (ASDs) are a group of developmental disabilities characterized by impairments in social interaction and communication and by restricted, repetitive, and stereotyped patterns of behavior. Symptoms typically are apparent before age 3 years. The complex nature of these disorders, coupled with a lack of biologic markers for diagnosis and changes in clinical definitions over time, creates challenges in monitoring the prevalence of ASDs. Accurate reporting of data is essential to understand the prevalence of ASDs in the population and can help direct research.

#### Period Covered: 2008.

**Description of System:** The Autism and Developmental Disabilities Monitoring (ADDM) Network is an active surveillance system that estimates the prevalence of ASDs and describes other characteristics among children aged 8 years whose parents or guardians reside within 14 ADDM sites in the United States. ADDM does not rely on professional or family reporting of an existing ASD diagnosis or classification to ascertain case status. Instead, information is obtained from children's evaluation records to determine the presence of ASD symptoms at any time from birth through the end of the year when the child reaches age 8 years. ADDM focuses on children aged 8 years because a baseline study conducted by CDC demonstrated that this is the age of identified peak prevalence. A child is included as meeting the surveillance case definition for an ASD if he or she displays behaviors (as described on a comprehensive evaluation completed by a qualified professional) consistent with the American Psychiatric Association's Diagnostic and Statistical Manual-IV, Text Revision (DSM-IV-TR) diagnostic criteria for any of the following conditions: Autistic Disorder; Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS, including Atypical Autism); or Asperger Disorder. The first phase of the ADDM methodology involves screening and abstraction of comprehensive evaluations completed by professional providers at multiple data sources in the community. Multiple data sources are included, ranging from general pediatric health clinics to specialized programs for children with developmental disabilities. In addition, many ADDM sites also review and abstract records of children receiving special education services in public schools. In the second phase of the study, all abstracted evaluations are reviewed by trained clinicians to determine ASD case status. Because the case definition and surveillance methods have remained consistent across all ADDM surveillance years to date, comparisons to results for earlier surveillance years can be made. This report provides updated ASD prevalence estimates from the 2008 surveillance year, representing 14 ADDM areas in the United States. In addition to prevalence estimates, characteristics of the population of children with ASDs are described, as well as detailed comparisons of the 2008 surveillance year findings with those for the 2002 and 2006 surveillance years.

Results: For 2008, the overall estimated prevalence of ASDs among the 14 ADDM sites was 11.3 per 1,000 (one in 88) children aged 8 years who were living in these communities during 2008. Overall ASD prevalence estimates varied widely across all sites (range: 4.8–21.2 per 1,000 children aged 8 years). ASD prevalence estimates also varied widely by sex and by racial/ethnic group. Approximately one in 54 boys and one in 252 girls living in the ADDM Network communities were identified as having ASDs. Comparison of 2008 findings with those for earlier surveillance years indicated an increase in estimated ASD prevalence of 23% when the 2008 data were compared with the data for 2006 (from 9.0 per 1,000 children aged 8 years in 2006 to 11.0 in 2008 for the 11 sites that provided data for both surveillance years) and an estimated increase of 78% when the 2008 data were compared with the data for 2002 (from 6.4 per 1,000 children aged 8 years in 2002 to 11.4 in 2008 for the 13 sites that provided data for both surveillance years). Because the ADDM Network sites do not make up a nationally representative sample, these combined prevalence estimates should not be generalized to the United States as a whole.

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**Interpretation:** These data confirm that the estimated prevalence of ASDs identified in the ADDM network surveillance populations continues to increase. The extent to which these increases reflect better case ascertainment as a result of increases in awareness and access to services or true

increases in prevalence of ASD symptoms is not known. ASDs continue to be an important public health concern in the United States, underscoring the need for continued resources to identify potential risk factors and to provide essential supports for persons with ASDs and their families.

**Public Health Action:** Given substantial increases in ASD prevalence estimates over a relatively short period, overall and within various subgroups of the population, continued monitoring is needed to quantify and understand these patterns. With 5 biennial surveillance years completed in the past decade, the ADDM Network continues to monitor prevalence and characteristics of ASDs and other developmental disabilities for the 2010 surveillance year. Further work is needed to evaluate multiple factors contributing to increases in estimated ASD prevalence over time. ADDM Network investigators continue to explore these factors, with a focus on understanding disparities in the identification of ASDs among certain subgroups and on how these disparities have contributed to changes in the estimated prevalence of ASDs. CDC is partnering with other federal and private partners in a coordinated response to identify risk factors for ASDs and to meet the needs of persons with ASDs and their families.

### Introduction

Autism spectrum disorders (ASDs) are a group of developmental disabilities characterized by impairments in social interaction and communication and by restricted, repetitive, and stereotyped patterns of behavior (1). Symptoms typically are apparent before age 3 years. Since the early 1990s, elevated public concern about continued reported increases in the number of children receiving services for ASDs and reports of higher-than-expected ASD prevalence estimates have underscored the need for systematic public health monitoring of ASDs (2). Tracking the prevalence of ASDs over time poses unique challenges because of the complex nature of these disorders, a lack of biologic markers for diagnosis, and changes in clinical definitions over time.

In 2000, CDC established the Autism and Developmental Disabilities Monitoring (ADDM) Network to collect data that would provide estimates of the prevalence of ASDs and other developmental disabilities in the United States (2). Initial reports from the ADDM Network provided ASD prevalence estimates from six sites for the 2000 surveillance year (3) and from 14 sites for the 2002 surveillance year (4). Estimates of ASD prevalence among children aged 8 years were similar for both surveillance years. Data combined from all sites in each respective surveillance year yielded overall ASD prevalence estimates of 6.7 per 1,000 children aged 8 years in 2000 (range: 4.5–9.9) and 6.6 per 1,000 in 2002 (range: 3.3–10.6), or one in every 150 children aged 8 years.

The subsequent ADDM Network report provided data on estimated ASD prevalence among children aged 8 years for 2004 (eight sites) and 2006 (11 sites) (5). When data from all sites were combined, overall estimated ASD prevalence was 8.0 per 1,000 children aged 8 years in 2004 (range: 4.6–9.8), or one in every 125 children, and 9.0 per 1,000 in 2006 (range: 4.2–12.1), or one in every 110 children aged 8 years. ASD prevalence estimates for the 2002 and 2006 surveillance years were compared (5). All 10 ADDM sites

that provided data for both surveillance years reported an increase in estimated ASD prevalence (range: 27%–95%). By 2006, the combined estimated prevalence of ASDs in ADDM Network sites approached 1% of children aged 8 years, a 4-year increase of 57% among sites that provided data for both the 2002 and 2006 surveillance years (5). Some of the increase in estimated ASD prevalence might be attributed to improved identification, particularly among certain subgroups (e.g., children without intellectual disability and Hispanic children). These data indicated the importance of continuing to monitor trends in ASD prevalence and of accelerating the pace of research into risk factors and effective interventions.

Certain studies from the United States, Europe, and Asia have reported ASD prevalence estimates based on national survey data, statewide administrative data, or community screening approaches (6-10). Results from these studies are generally consistent with those reported by the ADDM Network, although some international prevalence estimates are higher. In the United States, parent-reported data from the 2007 National Survey of Children's Health indicated an overall estimated prevalence of 11.0 per 1,000 children aged 3–17 years (6), and data from the National Health Interview Survey demonstrated a nearly fourfold increase in estimated ASD prevalence between the 1997–1999 and the 2006–2008 surveillance periods (7). A British study that employed both a questionnaire and direct screening methods estimated an ASD prevalence of close to 1% of children aged 5-9 years during the 2003 and 2004 school years (8,9). A recent study based on population screening and direct assessment in South Korea estimated overall ASD prevalence of 26.4 per 1,000 children aged 7-12 years in 2006 (10).

This report provides updated ASD prevalence estimates from the ADDM Network for the 2008 surveillance year, representing 14 sites in the United States. In addition to prevalence estimates, characteristics of the population of children with ASDs are described. This report is intended to communicate the latest available ASD prevalence estimates

from the ADDM Network and to provide basic comparisons with estimates for earlier ADDM surveillance years. More focused efforts are underway to analyze available data on multiple factors influencing the identification of children with ASDs and potential changes in risk factors over time.

# Methods Study Sites

The Children's Health Act of 2000 (11) authorized CDC to create the ADDM Network, the only collaborative network to estimate the prevalence of ASDs in the United States. ADDM has multiple goals: 1) to obtain as complete a count as possible of the number of children with ASDs in each project area, 2) to report comparable population-based ASD prevalence estimates from different sites and determine if these rates are changing over time, 3) to study whether autism is more common among some groups of children than among others, and 4) to provide descriptive data on the population of children with ASDs. Since the ADDM Network's inception in 2000, CDC has funded grantees in 14 states (Alabama, Arizona, Arkansas, Colorado, Florida, Maryland, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Utah, West Virginia, and Wisconsin). The ADDM Network implements a multisite, multiple-source, records-based surveillance methodology based on a model originally implemented by CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) (12). The case definition and surveillance methods, which have been described in detail previously (2-5,12,13), have remained consistent over time, enabling comparisons across multiple surveillance years. ADDM focuses on children aged 8 years because a baseline ASD prevalence study conducted by MADDSP demonstrated that this is the age of identified peak prevalence (12). MADDSP represents one ADDM site in Georgia, and the remaining ADDM projects are administered through state health departments or through universities working on behalf of their state health departments to collect or receive information used for protecting public health. Sites were selected through a competitive objective review process on the basis of their ability to conduct active, records-based surveillance of ASDs; they were not selected to be a nationally representative sample. Each ADDM site participating in the 2008 surveillance year functioned as a public health authority under the HIPAA Privacy Rule and met applicable local Institutional Review Board and privacy/ confidentiality requirements under 45 CFR 46 (14).

### **Case Ascertainment**

ADDM is an active surveillance system that does not rely on professional or family reporting of an existing diagnosis or classification to ascertain ASD case status. Case determination is completed in two phases. The first phase involves screening and abstraction of records at multiple data sources in the community. All abstracted evaluations then are compiled and reviewed by trained clinicians to determine ASD case status in the second phase of the study. In the first phase, a broad net is cast to screen thousands of records and identify a subset of children with general symptoms of ASDs, whereas a much more strict case definition is applied during the second phase of the study. Because children's records are screened at multiple data sources, developmental assessments completed by a wide range of health and education providers are included. Data sources are categorized as either 1) education source type, including evaluations to determine eligibility for special education services or 2) health source type, including diagnostic and developmental assessments from psychologists, neurologists, developmental pediatricians, physical therapists, occupational therapists, speech/language pathologists, and other providers. Agreements to access records are made at the institutional level in the form of contracts, memoranda, or other formal agreements. All ADDM Network sites have agreements in place to access records at health sources; however, four ADDM sites (Alabama, Florida, Missouri, and Wisconsin) have not been granted access to records at education sources, and in one site (Colorado), parents are notified directly about the study and may request that their children's education records be excluded.

In the first phase of the study, ADDM Network sites identify source records to review based on a child's year of birth and either 1) eligibility classifications in special education or 2) International Classification of Diseases, Ninth Revision (ICD-9) billing codes (Box) for select childhood disabilities or psychological conditions. Children's records are screened to confirm year of birth and residency in the surveillance area at some time during the surveillance year. For children meeting age and residency requirements, the source files are screened for certain behavioral or diagnostic descriptions defined by ADDM as "triggers" for abstraction (e.g., child does not initiate interactions with others, prefers to play alone or engage in solitary activities, or has received a documented ASD diagnosis). If abstraction "triggers" are found, evaluation information from birth through the current surveillance year is abstracted into a single composite record for each child.

In the second phase of the ADDM methodology, the abstracted composite evaluation files are de-identified and

BOX. Core list of International Classification of Diseases, Ninth Revision billing codes used by all Autism and Developmental Disabilities Monitoring Network sites to identify records for review at health sources

_		
	299.0	Autistic disorder
	299.1	Childhood disintegrative disorder
	299.8	Other specified pervasive developmental disorders
	299.9	Unspecified pervasive developmental disorder
	315.30	Developmental speech or language disorder
	315.31	Expressive language disorder
	315.32	Mixed receptive-expressive language disorder
	315.4	Developmental coordination disorder
	315.5	Mixed development disorder
	315.8	Other specified delays in development
	315.9	Unspecified delay in development
	317.0	Mild mental retardation
	318.0	Moderate mental retardation
	318.1	Severe mental retardation
	318.2	Profound mental retardation
	319.0	Unspecified mental retardation
	330.8	Other specified cerebral degenerations in childhood
	348.3	Encephalopathy, not elsewhere classified
	348.8	Other conditions of brain
	348.9	Unspecified condition of brain
	759.5	Tuberous sclerosis
	759.83	Fragile X syndrome
	771.0	Congenital rubella
	783.42	Delayed milestones
	V79.2	Screening, mental retardation
	V79.3	Screening, developmental handicaps in early childhood
	V79.8	Screening, other specified mental disorders and
		developmental handicaps
	V79.9	Screening, unspecified mental disorder and
		developmental handicap

reviewed systematically by trained clinicians to determine ASD case status using a coding scheme based on the American Psychiatric Association's Diagnostic and Statistical Manual-IV, Text Revision (DSM-IV-TR) (1) criteria for ASDs. A child is included as meeting the surveillance case definition for ASD if he or she displays behaviors at any time from birth through the end of the year when the child reaches age 8 years, as described on a comprehensive evaluation by a qualified professional, that are consistent with the DSM-IV-TR diagnostic criteria for any of the following conditions: Autistic Disorder; Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS, including Atypical Autism); or Asperger Disorder.

# **Descriptive Characteristics**

In addition to coding DSM-IV-TR diagnostic criteria for determining ASD case status, clinician reviewers systematically record additional findings from each abstracted evaluation. For example, reviewers note any concerns regarding the child's development by age 3 years, with specific focus on the development of social, language, and imaginative play skills as well as any mention of regression or plateau in skill development. The diagnostic conclusions from each evaluation record also are summarized for each child, including notation of any ASD diagnosis by subtype, when available. Children are considered to have a previously documented ASD classification if they received a diagnosis of Autistic Disorder, PDD-NOS, Asperger Disorder, or ASD that was documented in an abstracted evaluation or by an ICD-9 billing code at any time from birth through the end of the year when they reached age 8 years, or if they received special education services under an autism eligibility during the surveillance year.

Information on children's functional skills also is abstracted from source records, when available, including scores on tests of intellectual ability. Children are classified as having intellectual disability if they had an intelligence quotient (IQ) score of ≤70 on their most recent test available in the record. Borderline intellectual ability is defined as having an IQ score of 71–85, and average or above-average intellectual ability is defined as having an IQ score of >85. In the absence of a specific IQ score, an examiner's statement about the child's intellectual ability, if available, is used to classify the child in one of these three levels.

# **Quality Assurance**

All sites follow the same quality assurance standards established by the ADDM Network. For Phase 1, screening and abstraction of source records are monitored for accuracy on a periodic basis. In Phase 2, ongoing inter-rater reliability checks are conducted on a blinded, random sample of  $\geq \! 10\%$  of records undergoing clinician review. For the 2008 surveillance year, when comparison samples from all sites are combined, inter-rater agreement on case status (confirmed ASD versus not ASD) was 90.2% ( $\kappa = 0.8$ ); this exceeds the minimal quality assurance standards established by the ADDM Network for all surveillance years.

# **Analytic Methods**

Population denominators for calculating ASD prevalence estimates were obtained from CDC's National Center for Health Statistics (NCHS) vintage 2009 bridged-race postcensal population estimates for calculating vital rates (15). NCHS provides estimated population counts by state, county, single year of age, race, ethnic origin, and sex. Population denominators for the 2008 surveillance year were compiled from the postcensal estimates of children aged 8 years living in the counties under surveillance by each ADDM site (Table 1).

For two sites (Arizona and Utah), partial counties were included in the 2008 surveillance area, so geographic boundaries were defined by the school district(s) included in the surveillance area. Counts of children residing in outlying school districts were subtracted from the county-level postcensal denominators using school enrollment data from the U.S. Department of Education's National Center for Education Statistics (16). Enrollment counts of students in third grade during the 2008-09 school year were noted to differ from NCHS postcensal population estimates; this difference was attributable primarily to children being enrolled out of the customary grade for their age, in private schools, or home-schooled. Because these differences varied by race and sex within the applicable counties, a race- and sex-specific adjustment factor based on enrollment data was applied to the NCHS data to derive school district-specific denominators for these two states.

For comparison of prevalence estimates across multiple time points, population estimates also were obtained from the NCHS vintage 2009 bridged-race postcensal population estimates (15) using the number of children aged 8 years living in the surveillance counties during 2002, 2006, and 2008. These population estimates differ slightly from those used in previous ADDM reports but represent the most recent available data (17) for evaluating changes in the prevalence of ASDs across multiple time points.

The race/ethnicity of each child whose records were abstracted was determined from information contained in source records or, if not found in the source file, from birth certificates (when available). Race- or ethnicity-specific prevalence estimates were calculated for five populations: non-Hispanic white, non-Hispanic black, Hispanic, Asian/Pacific Islander, and American Indian/Alaska Native. Prevalence results are reported as the total number of children meeting the ASD case definition per 1,000 children aged 8 years in the population in each race/ethnicity group. ASD prevalence also was calculated separately for males and females, as well as within each level of intellectual ability. Overall prevalence estimates include all children identified with ASDs regardless

of sex, race/ethnicity, or level of intellectual ability and thus are not affected by the availability of data on these characteristics.

Confidence intervals (CIs) for prevalence estimates were derived under the assumption that the observed counts of children identified with ASDs are random variables drawn from an underlying Poisson distribution. For the current report, chi-square tests, rate ratios (RRs), and percentage differences were calculated to compare prevalence estimates within and across sites and between surveillance years. A maximum value of p<0.05 was used for all tests of statistical significance. Results for all sites combined were based on pooled numerator and denominator data from all sites, in total and stratified by race/ethnicity, sex, and level of intellectual ability.

### **Evaluation Methods**

Certain education and health records could not be located for review. An analysis of the effect of these missing records on case ascertainment was conducted. This also included records affected by the passive consent process unique to the Colorado site. All children initially identified for screening were first stratified by two factors highly associated with final case status: information source (education type source only, health type source only, or both types of sources) and the presence or absence of either an ICD-9 code for ASD or autism special education eligibility. The potential number of cases missed because of missing records was estimated under the assumption that within each of these six strata, the proportion of children with missing records who ultimately would be confirmed as having ASDs would have been similar to that of children for whom no records were missing. Within each stratum, the proportion of children with no missing records who were confirmed as having ASDs was applied to the number of children with missing records to estimate the number of missed cases, and the estimates from all six strata were summed to calculate the total for each site.

All 2008 ADDM sites identified records to review at most health sources by searching based on a common list of ICD-9 billing codes. However, several sites reviewed records based on an expanded list of ICD-9 codes because they were conducting surveillance for other developmental disabilities in addition to ASDs (i.e., one or more of the following: cerebral palsy, intellectual disability, hearing loss, and vision impairment) or, in the case of Colorado, because they identified an additional billing code (781.3, lack of coordination) that is commonly used for children with ASDs in that community. To evaluate the potential impact on ASD prevalence, analysts calculated the proportion of children meeting the ASD surveillance case definition whose records were obtained solely on the basis of those additional codes.

TABLE 1. Number\* and percentage of children aged 8 years, by race/ethnicity and site — Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008

			Total	Wh non-Hi		Bla non-Hi		Hisp	anic	AI	이	AI/	AN
Site	Site/Institution	Surveillance area	No.	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Alabama	Univ of Alabama at Birmingham	32 counties in north and central Alabama	36,566	24,516	(67.0)	9,295	(25.4)	2,112	(5.8)	489	(1.3)	154	(0.4)
Arizona <sup>†</sup>	Univ of Arizona	Part of 1 county in metropolitan Phoenix	32,601	15,022	(46.1)	1,804	(5.5)	14,227	(43.6)	893	(2.7)	655	(2.0)
Arkansas	Univ of Arkansas for Medical Sciences	1 county (Pulaski) in metropolitan Little Rock	4,940	2,371	(48.0)	2,112	(42.8)	296	(6.0)	123	(2.5)	38	(0.8)
Colorado <sup>§</sup>	Colorado Dept of Public Health and Environment	1 county (Arapahoe) in metropolitan Denver	7,725	3,990	(51.7)	1,051	(13.6)	2,233	(28.9)	387	(5.0)	64	(8.0)
Colorado <sup>¶</sup>	Colorado Dept of Public Health and Environment	6 counties in metropolitan Denver (excludes Arapahoe)	29,336	16,923	(57.7)	1,390	(4.7)	9,660	(32.9)	1,179	(4.0)	184	(0.6)
Florida	Univ of Miami	1 county (Miami–Dade) in south Florida	29,366	7,013	(23.9)	6,328	(21.5)	15,540	(52.9)	445	(1.5)	40	(0.1)
Georgia	CDC	5 counties including metropolitan Atlanta	50,427	18,725	(37.1)	20,690	(41.0)	7,875	(15.6)	2,958	(5.9)	179	(0.4)
Maryland	Johns Hopkins Univ	6 counties in suburban Baltimore	27,022	18,337	(67.9)	5,796	(21.4)	1,347	(5.0)	1,467	(5.4)	75	(0.3)
Missouri	Washington Univ– St. Louis	5 counties including metropolitan St. Louis	25,668	17,718	(69.0)	6,153	(24.0)	891	(3.5)	816	(3.2)	90	(0.4)
New Jersey	Univ of Medicine and Dentistry of New Jersey	1 county (Union) in metropolitan Newark	7,082	3,096	(43.7)	1,601	(22.6)	2,050	(28.9)	322	(4.5)	13	(0.2)
North Carolina	Univ of North Carolina– Chapel Hill	11 counties in central North Carolina	36,913	21,038	(57.0)	9,414	(25.5)	4,977	(13.5)	1,353	(3.7)	131	(0.4)
Pennsylvania	Univ of Pennsylvania	1 metropolitan county (Philadelphia)	18,440	5,180	(28.1)	9,060	(49.1)	3,067	(16.6)	1,067	(5.8)	66	(0.4)
South Carolina	Medical Univ of South Carolina	23 counties in Coastal and Pee Dee regions	23,769	12,506	(52.6)	9,566	(40.2)	1,285	(5.4)	295	(1.2)	117	(0.5)
Utah <sup>†</sup>	Univ of Utah	Part of 1 county in northern Utah	2,123	899	(42.3)	116	(5.5)	902	(42.5)	171	(8.1)	35	(1.6)
Wisconsin	Univ of Wisconsin–Madison	10 counties in south eastern Wisconsin	34,451	22,479	(65.2)	5,818	(16.9)	4,720	(13.7)	1,264	(3.7)	170	(0.5)

Abbreviations: API = Asian/Pacific Islander; AI/AN = American Indian/ Alaska Native.

Funding for most ADDM Network sites participating in the 2008 surveillance year was awarded for a 4-year cycle during 2006–2010, during which time data were collected for the 2006 and 2008 surveillance years. However, three additional sites (Arkansas, New Jersey, and Utah) were funded during 2009–2010 to collect data for the 2008 surveillance year only. These three sites also had participated in the ADDM 2002 surveillance year and were able to compare their 2008 prevalence results to those from 2002. However, because only 1 year of funding was available to complete the study, these three sites covered smaller surveillance areas in 2008 compared with other sites and with the earlier surveillance year(s) in which these three returning sites participated. This enabled the three sites to complete surveillance year 2008 on the same timeline as other ADDM Network sites. However, this abbreviated

timeline required that population denominators for each of the three returning sites be fewer than 10,000 children, potentially yielding less representative prevalence estimates for Arkansas, New Jersey, and Utah. Results from the ADDM 2004 surveillance year were not compared with 2008 results because only eight of the 14 sites completed both studies, and the 2004 surveillance year represented a smaller scale, optional effort based on available resources.

Seven of the 14 sites participating in the 2008 surveillance year included a different mix of counties or school districts in 2008 compared with 1 or more previous surveillance years. For these sites, numerators and denominators for between-year comparisons were restricted systematically to residents of the core surveillance area that were common across all surveillance years in a given analysis (i.e., 2008-to-2002 ratios, 2008-to-2006 ratios,

<sup>\*</sup> Total numbers of children aged 8 years in each surveillance area were obtained from CDC's National Center for Health Statistics vintage 2009 postcensal population estimates.

<sup>†</sup> Denominator excludes school districts that were not included in the surveillance area, calculated from National Center on Education Statistics enrollment counts of third graders during the 2008–2009 school year.

<sup>§</sup> Colorado health and education source type surveillance area.

<sup>¶</sup> Expanded Colorado health source type only surveillance area.

and statistics that include all 3 surveillance years). Numerators for these comparisons were selected based on the child's county of residency or, for sites with surveillance areas defined by school districts, based on the child's census block group of residency within school district boundaries. Denominators for betweenyear comparisons were based on county-level NCHS postcensal estimates for the core surveillance area that was included during both surveillance years in a given comparison. For sites with surveillance areas defined by school districts, only those school districts included in both surveillance years were included when denominators for between-year comparisons were calculated. For these sites, county-level population estimates were adjusted according to school enrollment data in the same manner as denominators for the 2008 surveillance year were computed but further restricted to the school districts included in both surveillance years in a given comparison. Sites adjusting their denominators in this manner included Arizona for both the 2008-to-2006 and the 2008-to-2002 comparisons, as well as New Jersey and Utah for the 2008-to-2002 comparisons (school districts were used in defining surveillance areas for New Jersey in 2002 and Utah in 2008). Comparisons between surveillance years were not affected by any changes in sites' agreements to access education records because no sites had access to education sources for one surveillance year but not for the other.

### Results

The 14 ADDM sites that provided data for the 2008 surveillance year covered a total population of 337,093 children aged 8 years, which represented 8.4% of the U.S. population of children that age in 2008 (13). A total of 48,247 source records for 38,253 children were reviewed at education and health sources. Of these, the source records of 6,739 children met the criteria for abstraction, which was 17.5% of the total number of children whose source records were reviewed and 2% of the total population under surveillance (range: 1.0% [Alabama]–6.3% [Utah]). During clinician review, 3,820 children (57%) were confirmed as meeting the ASD surveillance case definition (range: 30% [Arkansas]–74% [North Carolina]). The number of evaluations abstracted for each child ultimately identified as having an ASD varied (median: 5; range: 3 [Florida and North Carolina]–10 [Utah].

#### **Overall ASD Prevalence Estimates**

When data from all 14 ADDM sites in the 2008 surveillance year were combined, overall estimated ASD prevalence was 11.3 per 1,000 (one in 88) children aged 8 years (range: 4.8 [Alabama]–21.2 [Utah]) (Table 2). Overall estimated

prevalence of ASDs was significantly lower in Alabama (4.8 per 1,000) than in any other site. Utah had the highest estimated ASD prevalence (21.2 per 1,000), which was significantly higher than all other sites except Arizona and New Jersey. The overall estimated ASD prevalence in New Jersey (20.5 per 1,000) was significantly higher than in any other site except Utah.

On average, estimated ASD prevalence was significantly higher in ADDM sites that had access to education sources compared with sites that relied solely on health sources to identify cases (RR: 1.5; 95% CI = 1.4–1.7; p<0.01). Relative differences among sites in prevalence estimates and 95% CIs are compared by access to education records and population size covered (Figure 1). In sites with access to both health and education sources, the proportion of ASD cases identified exclusively from education sources ranged from 10% in Arkansas to 72% in Arizona. One site (Colorado) was able to access education records in only one county but completed the study in six additional counties based on health records alone. In the one Colorado county with access to both education and health records, estimated ASD prevalence was almost twice as high (11.8 per 1,000) as in the six Colorado counties with access to health sources only (6.4 per 1,000). For this reason, Colorado results from the one county with access to both education and health records are considered to represent all children with ASDs more completely than results from the remaining six counties.

# Prevalence by Sex and Race/Ethnicity

Combining data from all 14 ADDM sites, estimated ASD prevalence was 18.4 per 1,000 (one in 54) males and 4.0 per 1,000 (one in 252) females (RR: 4.6 for all sites combined). ASD prevalence estimates were significantly (p<0.01) higher among boys than among girls in all 14 ADDM sites, with male-to-female prevalence ratios ranging from 2.7 in Utah to 7.2 in Alabama.

Estimated ASD prevalence also varied by race and ethnicity (Table 2). When data from all sites were combined, the estimated prevalence among non-Hispanic white children (12.0 per 1,000) was significantly greater than that among non-Hispanic black children (10.2 per 1,000) and Hispanic children (7.9 per 1,000). Estimated ASD prevalence was significantly lower among Hispanic children than among non-Hispanic white children in nine sites and significantly lower than among non-Hispanic black children in five sites. Only one site (Florida) identified a significantly higher ASD prevalence among Hispanic children compared with either non-Hispanic white or non-Hispanic black children. New Jersey was the only

TABLE 2. Estimated prevalence\* of autism spectrum disorders (ASDs) per 1,000 children aged 8 years, by sex and race/ethnicity — Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008

						Sex			_
		Total no.		Total <sup>†</sup>		Male	F	emale	- - Male-to-female
Site	Total no.	with ASDs	Prev	95% CI	Prev	95% CI	Prev	95% CI	prev ratio§
Alabama	36,566	174	4.8	(4.1–5.5)	8.1	(7.0-9.5)	1.1	(0.7–1.8)	7.2
Arizona	32,601	507	15.6	(14.3-17.0)	25.1	(22.8-27.6)	5.4	(4.4-6.7)	4.6
Arkansas	4,940	52	10.5	(8.0-13.8)	17.5	(13.0-23.6)	3.6	(1.9-7)	4.8
Colorado <sup>¶</sup>	7,725	91	11.8	(9.6-14.5)	20.1	(16.1-25.0)	2.9	(1.6-5.3)	6.8
Colorado**	29,336	188	6.4	(5.6-7.4)	10.4	(8.9-12.2)	2.2	(1.6-3.1)	4.7
Florida	29,366	211	7.2	(6.3-8.2)	11.3	(9.7-13.1)	2.9	(2.1-3.9)	3.9
Georgia	50,427	601	11.9	(11.0-12.9)	19.6	(18.0-21.4)	3.8	(3.1-4.6)	5.2
Maryland	27,022	336	12.4	(11.2-13.8)	20.5	(18.3-23.1)	3.9	(2.9-5.1)	5.3
Missouri	25,668	357	13.9	(12.5-15.4)	21.6	(19.2-24.3)	5.9	(4.7-7.4)	3.7
New Jersey	7,082	145	20.5	(17.4-24.1)	34.2	(28.7-40.7)	5.8	(3.8 - 9.1)	5.8
North Carolina	36,913	525	14.2	(13.1-15.5)	23.1	(21.0-25.3)	5.1	(4.1-6.2)	4.5
Pennsylvania	18,440	245	13.3	(11.7-15.1)	22.2	(19.4-25.4)	4.3	(3.1-5.8)	5.2
South Carolina	23,769	264	11.1	(9.8-12.5)	18.3	(16.1-20.9)	3.5	(2.6-4.8)	5.2
Utah	2,123	45	21.2	(15.8-28.4)	31.7	(22.4-44.8)	11.7	(6.8-20.1)	2.7
Wisconsin	34,451	267	7.8	(6.9-8.7)	11.7	(10.2-13.4)	3.7	(2.9-4.7)	3.2
Total	337,093	3,820	11.3	(11.0–11.7)	18.4	(17.7–19.0)	4.0	(3.7-4.3)	4.6

See table footnotes below.

TABLE 2. (Continued) Estimated prevalence\* of autism spectrum disorders (ASDs) per 1,000 children aged 8 years, by sex and race/ethnicity — Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008

				Race/Et	thnicity				Prev ratio				
	White	, non-Hispanic	Black, non-Hispanic			Hispanic		API	White-to-	White-to-	Black-to-		
Site	Prev	95% CI	Prev	95% CI	Prev	95% CI	Prev	95% CI	black	Hispanic	Hispanic		
Alabama	5.0	(4.2-6.0)	4.0	(2.9–5.5)	1.4	(0.5-4.4)	4.1	(1.0–16.4)	1.3	3.5 <sup>††</sup>	2.8		
Arizona	20.7	(18.5-23.1)	16.1	(11.2-23.1)	8.9	(7.5-10.6)	19.0	(11.8-30.6)	1.3	2.3 <sup>§§</sup>	1.8 <sup>§§</sup>		
Arkansas	13.5	(9.5-19.1)	7.1	(4.3-11.8)	10.1	(3.3-31.4)	11	_	1.9 <sup>††</sup>	1.3	0.7		
Colorado <sup>¶</sup>	14.8	(11.5-19.1)	10.5	(5.8-18.9)	6.7	(4.1-11.1)	2.6	(0.4-18.3)	1.4	2.2 <sup>§§</sup>	1.6 <sup>§§</sup>		
Colorado**	7.3	(6.1-8.7)	6.5	(3.4-12.4)	3.5	(2.5-4.9)	0.9	(0.1-6.0)	1.1	2.1 <sup>§§</sup>	1.8		
Florida	4.6	(3.2-6.5)	3.0	(1.9-4.7)	8.2	(6.9 - 9.8)	2.2	(0.3-16)	1.5	0.6 <sup>§§</sup>	0.4 <sup>§§</sup>		
Georgia	11.8	(10.3-13.5)	11.9	(10.5-13.5)	7.1	(5.5-9.2)	15.9	(11.9-21.1)	1.0	1.7 <sup>§§</sup>	1.7 <sup>§§</sup>		
Maryland	12.9	(11.4-14.7)	11.7	(9.3-14.9)	5.9	(3-11.9)	8.2	(4.6-14.4)	1.1	2.2 <sup>††</sup>	2.0		
Missouri	14.6	(12.9-16.5)	9.3	(7.1-12)	9.0	(4.5-18)	9.8	(4.9-19.6)	1.6 <sup>§§</sup>	1.6	1.0		
New Jersey	21.0	(16.5-26.8)	20.6	(14.7-29)	20.0	(14.7-27.2)	3.1	(0.4-22)	1.0	1.0	1.0		
North Carolina	14.6	(13.1-16.4)	15.4	(13.1-18.1)	7.6	(5.6-10.5)	11.8	(7.2-19.3)	1.0	1.9 <sup>§§</sup>	2.0 <sup>§§</sup>		
Pennsylvania	14.3	(11.4-17.9)	12.7	(10.6-15.2)	9.1	(6.3-13.2)	8.4	(4.4-16.2)	1.1	1.6 <sup>††</sup>	1.4		
South Carolina	10.2	(8.6-12.2)	9.9	(8.1-12.1)	7.0	(3.6-13.5)	_	_	1.0	1.5	1.4		
Utah	40.0	(28.9-55.5)	25.9	(8.3-80.2)	4.4	(1.7-11.8)	_	_	1.5	9.0 <sup>§§</sup>	5.8 <sup>††</sup>		
Wisconsin	8.6	(7.5-9.9)	5.0	(3.5-7.2)	3.8	(2.4-6.1)	2.4	(0.8-7.4)	1.7 <sup>§§</sup>	2.3 <sup>§§</sup>	1.3		
Total	12.0	(11.5–12.5)	10.2	(9.5-10.9)	7.9	(7.2-8.6)	9.7	(8.1–11.6)	1.2 <sup>§§</sup>	1.5 <sup>§§</sup>	1.3 <sup>§§</sup>		

**Abbreviations:** CI = confidence interval; API = Asian/Pacific Islander.

site that identified approximately the same estimated ASD prevalence among non-Hispanic white children, non-Hispanic black children, and Hispanic children. Estimates for Asian/Pacific Islander children ranged from 2.2 to 19.0 per 1,000

although wide confidence intervals suggest that these findings should be interpreted with caution.

<sup>\*</sup> Per 1,000 children aged 8 years.

<sup>†</sup> All children are included in the total regardless of race or ethnicity. Overall prevalence also includes children for whom race/ethnicity was unknown.

<sup>&</sup>lt;sup>§</sup> All sites identified statistically significantly higher prevalence among males compared with females (p<0.01).

<sup>¶</sup> Colorado health and education source type surveillance area.

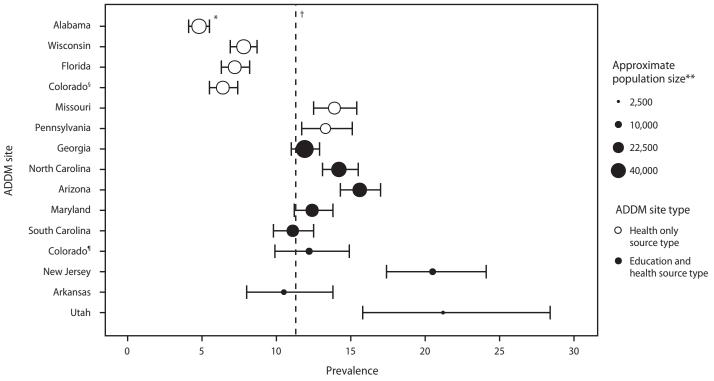
<sup>\*\*</sup> Expanded Colorado health source type only surveillance area.

 $<sup>^{\</sup>dagger\dagger}$  Prevalence ratio statistically significant at p<0.05.

<sup>§§</sup> Prevalence ratio statistically significant at p<0.01.

<sup>11</sup> No children identified in this group.

FIGURE 1. Estimated prevalence (per 1,000 population) of autism spectrum disorders (ASDs) among children aged 8 years, by access to education records and population size covered — Autism and Developmental Disabilities Monitoring Network (ADDM), 14 sites, United States, 2008



<sup>\* 95%</sup> confidence intervals.

# **Previously Documented ASD Classification**

Among all children meeting the ASD surveillance case definition, approximately 79% had a previously documented ASD classification (range: 67% [Colorado]-87% [Pennsylvania and Wisconsin]). The median age of earliest known ASD diagnosis documented in children's records (Table 3) varied by diagnostic subtype (Autistic Disorder: 48 months; ASD/ PDD: 53 months; Asperger Disorder: 75 months). Of the 2,627 children with a diagnostic subtype on record, 516 (20%) had different subtypes noted across multiple evaluations, suggesting instability in the initial subtype diagnosed for approximately one in five children. The age of earliest known diagnosis for all subtypes combined is not reported because of substantial variability in the median age at the earliest known ASD diagnosis by subtype, the proportion of children within each subtype category across the different ADDM sites, and the subtype noted across multiple evaluations for each child.

# **Special Education Eligibility**

Sites with access to education records collected information about the eligibility categories under which special education services were received in public schools (Table 4). Wide variation existed in the proportion of children with a primary eligibility category of autism (range: 39% [Colorado]–72% [North Carolina]). In Colorado, autism is a subcategory of physical disability, so the primary eligibility might have been documented as autism or physical disability, depending on the school district. Other common special education eligibilities included intellectual disability, health or physical disability, speech and language impairment, and specific learning disability, with these proportions also varying by site.

# **Intellectual Ability**

Data on intellectual ability are reported for the seven sites having information available for at least 70% of children who met the ASD case definition (Figure 2). When data from these seven sites were combined, 38% of children with ASDs were

<sup>&</sup>lt;sup>†</sup> Overall weighted ASD prevalence.

<sup>§</sup> Expanded Colorado health source type only surveillance area.

<sup>¶</sup> Colorado health and education source type surveillance area.

<sup>\*\*</sup> Size of dot represents total population of children aged 8 years residing in the surveillance area.

TABLE 3. Median age (in months) of earliest known autism spectrum disorder (ASD) diagnosis among children identified with autism spectrum disorders by age 8 years, and number and proportion within each diagnostic subtype — Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008

	Aut	istic disord	er		ASD/PDD		Aspe	rger disord	ler	Any spec diagi	
Site	Median age	No.	%	Median age	No.	%	Median age	No.	%	No.	%
Alabama	48	48	42	62	57	50	82	*	9	115	66
Arizona	56	182	63	54	84	29	76	24	8	290	57
Arkansas	55	_	39	46	18	50	88	_	11	36	69
Colorado <sup>†</sup>	52	26	46	54	23	40	79	_	14	57	63
Florida	36	64	44	43	73	50	59	_	7	147	70
Georgia	53	188	50	54	150	40	72	37	10	375	62
Maryland	59	98	40	67	127	52	79	21	9	246	73
Missouri	58	65	24	39	186	67	75	26	9	277	78
New Jersey	38	19	19	51	70	71	66	_	9	98	68
North Carolina	39	187	54	55	128	37	79	30	9	345	66
Pennsylvania	43	73	35	59	117	57	70	17	8	207	85
South Carolina	46	102	56	58	67	37	81	_	7	181	69
Utah	52	_	42	52	_	45	68	_	13	31	69
Wisconsin	46	79	36	52	116	52	74	27	12	222	83
Total	48	1,158	44	53	1,230	47	75	239	9	2,627	69

**Abbreviation:** PDD = pervasive developmental disorder – not otherwise specified.

TABLE 4. Number and percentage of children aged 8 years identified with autism spectrum disorders (ASDs) for whom special education data were available, by site and primary special education eligibility category — Autism and Developmental Disabilities Monitoring Network, nine sites with access to education records, United States, 2008

Special education category*	Arizona %	Arkansas %	Colorado† %	Georgia %	Maryland %	New Jersey %	North Carolina %	South Carolina %	Utah %
Autism	50.4	53.6	39.0 <sup>§</sup>	67.3	63.1	43.2	71.8	50.7	48.6
Emotional disturbance	7.1	0	2.6	3.1	3.9	2.2	2.2	1.5	14.3
Specific learning disability	10.6	0	0	4.0	7.1	10.1	6.4	5.4	8.6
Speech or language impairment	12.1	17.9	19.5	1.1	8.9	11.5	1.8	9.9	11.4
Hearing or visual impairment	0.2	3.6	0	0	0	0.7	0	1.0	0
Health or physical disability	6.2	14.3	27.3 <sup>§</sup>	4.9	7.8	19.4	7.5	13.8	0
Multiple disabilities	1.3	3.6	7.8	0	2.8	7.9	2.2	0.5	2.9
Intellectual disability	11.9	7.1	3.9	4.9	2.5	4.3	5.3	14.8	11.4
Developmental delay/preschool	0	0	0	14.8	3.9	0.7	2.7	2.5	2.9
Total no. of ASD cases (No./%¶)	507 (480/94.7)	52 (28/53.8)	91 (77/84.6)	601 (554/92.2)	336 (282/83.9)	145 (139/95.9)	525 (451/85.9)	264 (203/76.9)	45 (35/77.8)

<sup>\*</sup> Some state-specific categories were recoded or combined to match current U.S. Department of Education categories.

classified in the range of intellectual disability (i.e.,  $IQ \le 70$  or an examiner's statement of intellectual disability), 24% in the borderline range (IQ 71-85), and 38% had IQ scores >85 or an examiner's statement of average or above-average intellectual ability. The proportion of children classified in the range of intellectual disability ranged from 13% in Utah to 54% in South Carolina. The two sites with the highest proportions of children classified above the range of intellectual disability (IQ > 70) were Utah (87%) and New Jersey (73%). In all seven

sites reporting data on intellectual ability, a higher proportion of females with ASDs had intellectual disability compared with males, although the proportions differed significantly (52% for females and 35% for males; p<0.01) in only one site (North Carolina). When data from these seven sites were combined, 150 (46%) of 328 females with ASDs had IQ scores or examiners' statements indicating intellectual disability compared with 608 (37%) of 1,653 males.

<sup>\*</sup> Data not reported because N<15.

<sup>&</sup>lt;sup>†</sup> Colorado health and education source type surveillance area.

<sup>&</sup>lt;sup>†</sup> Colorado health and education source type surveillance area.

<sup>§</sup> Autism is a subcategory of physical disability in Colorado. The primary eligibility might have been documented as autism or physical disability, depending on the school district.

Number and percentage receiving special education services during 2008.

100 90 **□** IQ >85 80 IQ 71-85 IQ ≤70 70 60 Percentage 50 40 30 20 10 0 M

N. Carolina

S. Carolina

FIGURE 2. Most recent intelligence quotient (IQ) as of age 8 years among children identified with autism spectrum disorders (ASDs) for whom psychometric test data were available,\* by site and sex — Autism and Developmental Disabilities Monitoring Network, seven sites,† United States, 2008

Arizona

Georgia

New Jersey

# Evaluation of Missing Records and Expanded ICD-9 Codes

Arkansas

Underascertainment of ASDs because of missing records varied by site. The majority of sites estimated that the total number of children identified with ASDs might potentially have increased <5% had all records been located for review. However, it is estimated that ASD prevalence would have been 9% higher in Utah, 13% higher in Pennsylvania, 16% higher in Alabama and Maryland, and 26% higher in Florida.

Among the 12 sites reviewing records based on an expanded list of ICD-9 codes, five sites did not identify any children with ASDs solely on the basis of the expanded code list, whereas six sites identified approximately 1% or fewer, and Arkansas identified approximately 4% of the total number of children with ASDs solely on the basis of the expanded code list.

# Comparison Between 2006 and 2008 Prevalence Estimates

Utah

Total

Of the 11 sites completing both the 2006 and 2008 surveillance years, seven sites identified a higher prevalence of ASDs in 2008 compared with 2006, whereas three sites identified a similar prevalence in both years, and one site identified a lower prevalence in 2008 compared with 2006 (Table 5). Combining data from all 11 sites, estimated ASD prevalence increased 23% during 2006 to 2008 (9.0–11.0 per 1,000), ranging from -20% in Alabama (6.0–4.8 per 1,000) to +80% in Florida (4.0-7.2 per 1,000). The percentage increase in estimated ASD prevalence was similar for males (23%; 14.5-17.9 per 1,000) and for females (21%; 3.2-3.8 per 1,000). Six sites identified an increased prevalence among males in 2008, and the remaining five sites identified a similar prevalence among males in 2006 compared with 2008. Only three sites identified an increase in prevalence among females, while seven sites identified similar prevalence among females in

<sup>\*</sup> N=1,981

 $<sup>^\</sup>dagger$  Includes sites having information on intellectual ability available for at least 70% of children who met the ASD case definition.

TABLE 5. Estimated prevalence of autism spectrum disorders (ASDs) per 1,000 children aged 8 years, by sex and race/ethnicity — comparison of select earlier surveillance years to 2008, with rate ratio and percentage of prevalence change\* — Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2002, 2006, and 2008

	Alabama	Arizona	Arkansas	Colorado	Florida	Georgia	Maryland	Missouri	New Jersey	North Carolina	Pennsylvania	South Carolina	Utah	Wisconsin	All sites combined
Total ASD 2002 2008 Rate ratio (95% CI) % change	3.3 4.8 1.5 <sup>§</sup> (1.3–1.7) 45.6	7.9 15.6 2.0 <sup>§</sup> (1.9–2.1) 97.1	10.6 10.5 1.0 (0.6–1.4) -0.3	6.2 11.8 1.9 <sup>§</sup> (1.5–2.3) 88.8	†   	7.5 11.9 1.6 <sup>§</sup> (1.5–1.7) 58.3	7.0 12.1 1.7 <sup>§</sup> (1.5–1.9) 74.1	7.2 13.9 1.9 <sup>§</sup> (1.7–2.1) 92.7	11.1 20.3 1.8 <sup>§</sup> (1.5–2.1) 83.4	6.6 12.7 1.9 § (1.7–2.1) 93.6	5.2 13.3 2.6 <sup>§</sup> (2.4–2.8) 156.1	6.1 11.1 1.8 § (1.6–2) 83.0	8.3 21.2 2.6 <sup>§</sup> (2.1–3.1) 157.0	5.1 7.8 1.5 <sup>§</sup> (1.3–1.7) 51.7	6.4 11.4 1.8 <sup>§</sup> (1.7–1.9) 78.5
2006 2008 Rate ratio (95% CI) % change	6.0 4.8 0.8 <sup>¶</sup> (0.6–1) -20.4	15.8 15.6 1.0 (0.9–1.1) -1.8	_ _ _ _	7.4 11.8 1.6 <sup>§</sup> (1.3–1.9) 60.1	4.0 7.2 1.8 <sup>§</sup> (1.6–2) 79.8	10.1 11.9 1.2 <sup>§</sup> (1.1–1.3) 18.0	9.1 12.4 1.4 <sup>§</sup> (1.2–1.6) 36.7	12.1 13.9 1.1 (0.9–1.3) 14.9	_ _ _ _	10.2 12.4 1.2 <sup>¶</sup> (1–1.4) 21.0	8.4 13.3 1.6 <sup>§</sup> (1.4–1.8) 58.6	8.8 11.1 1.3 <sup>¶</sup> (1.1–1.5) 26.0	_ _ _ _	7.7 7.8 1.0 (0.8–1.2) 0.8	9.0 11.0 1.2 <sup>§</sup> (1.1–1.3) 22.6
Male 2002 2008 Rate ratio (95% CI) % change 2006 2008 Rate ratio (95% CI) % change	5.0 8.1 1.6 <sup>§</sup> (1.3–1.9) 61.5 9.0 8.1 0.9 (0.7–1.1)	12.9 25.1 2 <sup>§</sup> (1.8–2.2) 95.3 24.5 25.1 1.0 (0.9–1.1) 2.4	17.4 17.5 1.0 (0.6–1.4) 0.5 — — —	10.8 20.1 1.9 <sup>§</sup> (1.5–2.3) 86.2 11.3 20.1 1.8 <sup>§</sup> (1.4–2.2)	    6.9 11.3 1.6 <sup>§</sup> (1.4–1.8) 62.7	12.3 19.6 1.6 <sup>§</sup> (1.5–1.7) 59.7 16.5 19.6 1.2 <sup>¶</sup> (1.1–1.3) 18.6	10.6 20.2 1.9 <sup>§</sup> (1.7-2.1) 90.9 15.5 20.6 1.3 <sup>§</sup> (1.1-1.5) 32.4	11.2 21.6 1.9 <sup>§</sup> (1.7-2.1) 93.6 19.3 21.6 1.1 (0.9-1.3) 12.4	18.2 33.9 1.9 <sup>§</sup> (1.6–2.2) 86.2 — — —	10.8 20.6 1.9 <sup>§</sup> (1.7-2.1) 91.7 16.8 19.9 1.2 (1-1.4) 18.2	8.5 22.2 2.6§ (2.4–2.8) 160.0 13.2 22.2 1.7§ (1.5–1.9) 67.8	9.3 18.3 2.0 <sup>§</sup> (1.8–2.2) 97.7 14.6 18.3 1.3 <sup>¶</sup> (1.1–1.5) 25.8	15.6 31.7 2.0¶ (1.4–2.6) 103.3 — — —	7.8 11.7 1.5 <sup>§</sup> (1.3–1.7) 49.4 13.0 11.7 0.9 (0.7–1.1) -9.7	10.2 18.6 1.8 <sup>§</sup> (1.7-1.9) 81.6 14.5 17.9 1.2 <sup>§</sup> (1.1-1.3)
Female 2002 2008 Rate ratio (95% CI) % change	1.4 1.1 0.8 (0.2–1.4) -18.7	2.7 5.4 2.0 <sup>§</sup> (1.6–2.4) 102.6	3.7 3.6 1.0 (0.1–1.9) -2.7	1.4 2.9 2.1 (1–3.2) 110.0	_ _ _ _	2.6 3.8 1.4 <sup>¶</sup> (1.1–1.7) 44.6	3.2 3.6 1.1 (0.6–1.6) 13.2	3.0 5.9 1.9 <sup>§</sup> (1.5–2.3) 93.4	3.5 5.7 1.6 (0.9–2.3) 62.8	2.1 4.6 2.2 <sup>§</sup> (1.7–2.7) 115.1	1.8 4.3 2.4 <sup>§</sup> (1.9–2.9) 138.0	2.8 3.5 1.3 (0.8–1.8) 28.4	0.9 11.7 12.7 <sup>¶</sup> (10.7–14.7 1168.5	2.3 3.7 1.6 <sup>¶</sup>	2.4 4.0 1.6 <sup>§</sup> (1.5–1.7) 63.2
2006 2008 Rate ratio (95% CI) % change	2.8 1.1 0.4 <sup>§</sup> (0.1–0.9) -60.1	6.4 5.4 0.8 (0.5–1.1) -15.6	_ _ _ _	3.3 2.9 0.9 (0.1–1.7) -10.9	0.9 2.9 3.1 <sup>§</sup> (2.5–3.7) 212.0	3.4 3.8 1.1 (0.8–1.4) 11.9	2.4 3.9 1.6 <sup>¶</sup> (1.2–2) 63.7	4.8 5.9 1.2 (0.9–1.5) 23.8		3.4 4.6 1.4 (1–1.8) 37.4	3.3 4.3 1.3 (0.8–1.8) 28.3	2.6 3.5 1.4 (0.9–1.9) 34.7	_ _ _ _	2.3 3.7 1.6 <sup>¶</sup> (1.2–2) 59.1	3.2 3.8 1.2 <sup>§</sup> (1.1–1.3) 20.8
White, non-H 2002 2008 Rate ratio (95% CI) % change		9.9 20.7 2.1 <sup>§</sup> (1.9–2.3) 109.3	10.5 13.5 1.3 (0.8–1.8) 28.2	6.7 14.8 2.2 <sup>§</sup> (1.8–2.6) 122.4	_ _ _ _	8.8 11.8 1.3 <sup>§</sup> (1.1–1.5) 34.2	7.1 12.1 1.7 <sup>§</sup> (1.5–1.9) 71.0	7.6 14.6 1.9 <sup>§</sup> (1.7–2.1) 91.6	15.1 20.4 1.4 (1–1.8) 35.3	6.5 12.7 2.0 <sup>§</sup> (1.7–2.3) 96.0	7.6 14.3 1.9 <sup>§</sup> (1.5–2.3) 87.5	6.1 10.2 1.7 <sup>§</sup> (1.4–2) 69.0	15.1 40.0 2.7 <sup>§</sup> (2.1–3.3) 165.5	5.8 8.6 1.5 <sup>§</sup> (1.3–1.7) 47.8	7.0 11.9 1.7 <sup>§</sup> (1.6–1.8) 69.5
2006 2008 Rate ratio (95% CI) % change	5.8 5.0 0.9 (0.7–1.1) -13.3	18.3 20.7 1.1 (0.9–1.3) 13.1	_ _ _ _	6.6 14.8 2.2 <sup>§</sup> (1.7–2.7) 123.1	3.3 4.6 1.4 (0.9–1.9) 39.0	12.0 11.8 1.0 (0.8–1.2) –2.0	9.2 12.9 1.4 <sup>§</sup> (1.2–1.6) 40.3	13.7 14.6 1.1 (0.9–1.3) 6.7	_ _ _ _	12.0 12.2 1.0 (0.8–1.2) 1.7	10.3 14.3 1.4 (1–1.8) 38.2	7.3 10.2 1.4 <sup>¶</sup> (1.1–1.7) 40.9	_ _ _ _	8.7 8.6 1.0 (0.8–1.2) –1.3	10.0 11.5 1.2 <sup>§</sup> (1.1–1.3) 15.6
Black, non-H 2002 2008 Rate ratio (95% CI) % change	3.4 4.0 1.2 (0.7–1.7) 17.8	7.0 16.1 2.3 <sup>¶</sup> (1.6–3) 128.7	9.6 7.1 0.7 (0.1–1.4) -26.2	5.6 10.5 1.9 (0.8–3.0) 88.6		6.7 11.9 1.8 <sup>§</sup> (1.6–2) 77.9	6.7 12.6 1.9 <sup>§</sup> (1.5–2.3) 87.2	4.7 9.3 2.0 <sup>§</sup> (1.6–2.4) 97.6	6.4 20.6 3.2 <sup>§</sup> (2.5–3.9) 222.3	7.2 14.2 2.0 <sup>§</sup> (1.6–2.4) 98.3	4.1 12.7 3.1 <sup>§</sup> (2.8–3.4) 207.3	5.5 9.9 1.8 <sup>§</sup> (1.5–2.1) 79.2	0 25.9 NA** NA NA	3.6 5.0 1.4 (0.9–1.9) 37.2	5.5 10.5 1.9 <sup>§</sup> (1.8–2.0) 91.1
2006 2008 Rate ratio (95% CI) % change	6.7 4.0 0.6 <sup>¶</sup> (0.2–1) -40.6	16.8 16.1 1.0 (0.5–1.5) -4.5	_ _ _ _	12.1 10.5 0.9 (0.1–1.7) -13.7	1.5 3.0 2.0 (1.2–2.8) 96.1	9.3 11.9 1.3 <sup>¶</sup> (1.1–1.5) 27.8	7.8 11.7 1.5 <sup>¶</sup> (1.1–1.9) 50.8	5.1 9.3 1.8 <sup>§</sup> (1.4–2.2) 80.9	_ _ _ _	7.4 14.2 1.9 <sup>§</sup> (1.5–2.3) 91.2	7.4 12.7 1.7 <sup>§</sup> (1.4–2) 72.4	7.4 9.9 1.3 (1–1.6) 34.7	_ _ _ _	3.7 5.0 1.4 (0.8–2) 36.4	7.0 10.0 1.4 <sup>§</sup> (1.3–1.5) 42.1

See table footnotes on page 13.

2006 and 2008, and one site identified a lower ASD prevalence among females in 2008 compared with 2006.

Changes in estimated ASD prevalence during 2006–2008 also varied by race within individual ADDM sites and when combining data from all sites. The combined estimates

indicated a 16% increase in ASD prevalence among non-Hispanic white children (10.0–11.5 per 1,000), a 42% increase among non-Hispanic black children (7.0–10.0 per 1,000), and a 29% increase among Hispanic children (6.1–7.9 per 1,000). The percentage increase was statistically significant

TABLE 5. (Continued) Estimated prevalence of autism spectrum disorders (ASDs) per 1,000 children aged 8 years, by sex and race/ethnicity — comparison of select earlier surveillance years to 2008, with rate ratio and percentage of prevalence change\* — Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2002, 2006 and 2008

	Alabama	Arizona	Arkansas	Colorado	Florida	Georgia	Maryland	Missouri	New Jersey	North Carolina	Pennsylvania	South Carolina	Utah	Wisconsin	All sites combined
Hispanic															
2002	1.9	4.4	5.6	2.8	_	4.6	0	1.6	6.4	4.2	4.6	4.3	0	0.3	3.7
2008	1.4	8.9	10.1	6.7	_	7.1	4.3	9.0	20.1	6.9	9.1	7.0	4.4	3.8	7.7
Rate ratio	0.8	2.0 <sup>§</sup>	1.8	2.4	_	1.5	NA	5.5	3.1 <sup>§</sup>	1.7	2.0 <sup>¶</sup>	1.6	NA	13.2 <sup>¶</sup>	2.1 <sup>§</sup>
(95% CI)	(0.1-2.6)	(1.7-2.3)	(0.5-4.1)	(1.3-3.5)	_	(1.0-2.0)	NA	(3.4-7.6)	(2.4-3.8)	(0.9-2.5)	(1.4-2.6)	(0.3-2.9)	NA	(11.2-15.0)	(1.9-2.3)
% change	-26.3	102.3	80.4	139.3	_	54.3	NA	462.5	214.1	64.3	97.8	62.8	NA	1,166.7	109.2
2006	0.6	11.4	_	4.4	4.9	4.8	6.2	2.6	_	5.9	7.7	4.7	_	1.7	6.1
2008	1.4	8.9	_	6.7	8.2	7.1	5.9	9.0	_	6.7	9.1	7.0	_	3.8	7.9
Rate ratio	2.3	0.8 <sup>¶</sup>	_	1.5	1.7 <sup>§</sup>	1.5	1.0	3.5	_	1.1	1.2	1.5	_	2.2	1.3 <sup>§</sup>
(95% CI)	(0.1-4.6)	(0.6-1)	_	(0.6-2.4)	(1.4-2)	(1.1-1.9)	(0.1-2)	(2-5)	_	(0.5-1.7)	(0.6-1.8)	(0.4-2.6)	_	(1.3-3.1)	(1.2-1.4)
% change	132.8	-21.7	_	53.8	67.8	48.1	-3.9	246.7	_	12.3	18.7	47.7	_	122.8	29.1
IQ < 70															
2002	_	2.8	3.5	_	_	3.4	_	_	3.7	3.0	_	3.3	1.8	_	3.2
2008	_	4.9	3.6	_	_	4.6	_	_	4.9	4.1	_	5.1	2.4	_	4.6
Rate ratio	_	1.7 <sup>§</sup>	1.0	_	_	1.3 <sup>§</sup>	_	_	1.3	1.4 <sup>¶</sup>	_	1.6§	1.3	_	1.5 <sup>§</sup>
(95% CI)	_	(1.4-2)	(0.3-1.7)	_	_	(1.1–1.5)	_	_	(0.8-1.8)	(1.1-1.7)	_	(1.3-1.9)	(0.1-2.6)	_	(1.4–1.6)
% change	_	73.2	3.4	_	_	33.7	_	_	33.9	39.1	_	56.6	29.0	_	45.4
2006	_	5.9	_	_	_	3.5	_	_	_	3.8	_	3.9	_	_	4.2
2008	_	4.9		_	_	4.6	_	_	_	4.1	_	5.1		_	4.7
Rate ratio	_	0.8		_	_	1.3 <sup>§</sup>	_	_	_	1.1	_	1.3	_	_	1.1
(95% CI)	_	(0.6–1.0)			_	(1.1–1.5)		_	_	(0.8–1.4)	_	(1–1.6)	_	_	(1.0–1.2)
% change	_	-17.8	_	_	_	32.6	_	_	_	6.8	_	31.5	_	_	11.9
		17.0				32.0				0.0		31.3			11.2
IQ = 71-85		1.0	2.2			1.2			1.0	1.4		0.7	0		1.4
2002 2008	_	1.6 3.5	3.3 3.0	_	_	1.3 2.5	_	_	1.9	1.4	_	0.7	0 3.3	_	1.4 2.9
Rate ratio	_	3.3 2.2 <sup>§</sup>	0.9	_	_	2.5 2.0§	_	_	4.4 2.4 <sup>§</sup>	3.3 2.3 <sup>§</sup>	_	2.3 3.6 <sup>§</sup>	NA	_	2.9 2.2 <sup>§</sup>
(95% CI)	_	(1.9–2.5)	(0.2–1.6)	_	_	(1.7–2.3)	_	_	(1.7–3.1)	(1.9–2.7)	_	(3–4.2)	NA	_	(2.0–2.4)
% change	_	119.6	-8.2	_	_	96.9	_	_	135.1	130.5	_	(3–4.2) 255.4	NA NA	_	116.8
	_			_	_		_	_			_		INA		
2006	_	3.3	_	_	_	2.1	_	_	_	1.9	_	1.6	_	_	2.3
2008	_	3.5	_	_	_	2.5	_	_	_	3.2	_	2.3	_	_	2.8
Rate ratio	_	1.0	_	_	_	1.2	_	_	_	1.7 §	_	1.5	_	_	1.2 §
(95% CI)	_	(0.7–1.3)	_	_	_	(0.9–1.5)	_	_	_	(1.3–2.1)	_	(1.1–1.9)	_	_	(1.0–1.4)
% change	_	3.9	_	_	_	20.8	_	_	_	66.5	_	47.1	_	_	21.7
IQ >85															
2002	_	2.9	3.5	_	_	2.3	_	_	3.4	1.9	_	1.7	4.1	_	2.4
2008	_	6.5	2.6	_	_	4.0	_	_	8.3	4.8	_	2.0	12.3	_	4.7
Rate ratio	_	2.3 <sup>§</sup>	0.7	_	_	1.7 <sup>§</sup>	_	_	2.4 <sup>§</sup>	2.5 <sup>§</sup>	_	1.2	3.0 <sup>§</sup>	_	1.9§
(95% CI)	_	(2.1-2.5)	(0.1-1.4)	_	_	(1.5-1.9)	_	_	(1.9-2.9)	(2.1-2.9)	_	(0.8-1.6)	(2.2-3.8)	_	(1.8-2.0)
% change	_	127.3	-25.3	_	_	75.2	_	_	142.5	152.1	_	16.1	196.6	_	92.9
2006	_	5.5	_	_	_	3.7	_	_	_	4.1	_	2.1	_	_	3.9
2008	_	6.5	_	_	_	4.0	_	_	_	4.6	_	2.0	_	_	4.4
Rate ratio	_	1.2	_	_	_	1.1	_	_	_	1.1	_	1.0	_	_	1.1
(95% CI)	_	(1.0–1.4)	_	_	_	(0.9–1.3)	_	_	_	(0.8–1.4)	_	(0.6–1.4)	_	_	(1.0–1.2)
% change	_	18.4	_	_	_	8.6	_	_	_	13.1	_	-4.3	_	_	12.8

Abbreviations: CI = confidence interval; NA = not available.

for all three racial/ethnic groups. Alabama identified a lower prevalence among non-Hispanic black children in 2008, and Arizona identified a lower prevalence among Hispanic children in 2008 compared with 2006 results.

In the four sites with IQ test data available on at least 70% of children with ASDs in both the 2006 and 2008 surveillance years, the estimated prevalence of ASD with intellectual disability increased 12% on average (4.2–4.7 per 1,000), while the prevalence of ASD with borderline intellectual ability

increased 22% (2.3–2.8 per 1,000), and the prevalence of ASD with average or above-average intellectual ability increased 13% (3.9–4.4 per 1,000).

# Comparison Between 2002 and 2008 Prevalence Estimates

Thirteen ADDM sites completed both the 2002 and 2008 surveillance years, with all but one (Arkansas) identifying a

<sup>\*</sup> Rate ratios and percentage change calculated with 2008 as the numerator and either 2002 or 2006 as the denominator.

<sup>†</sup> Data not reported.

<sup>§</sup> Rate ratio statistically significant at p<0.01.

<sup>¶</sup>Rate ratio statistically significant at p<0.05.

<sup>\*\*</sup> A change cannot be calculated because the denominators are zero.

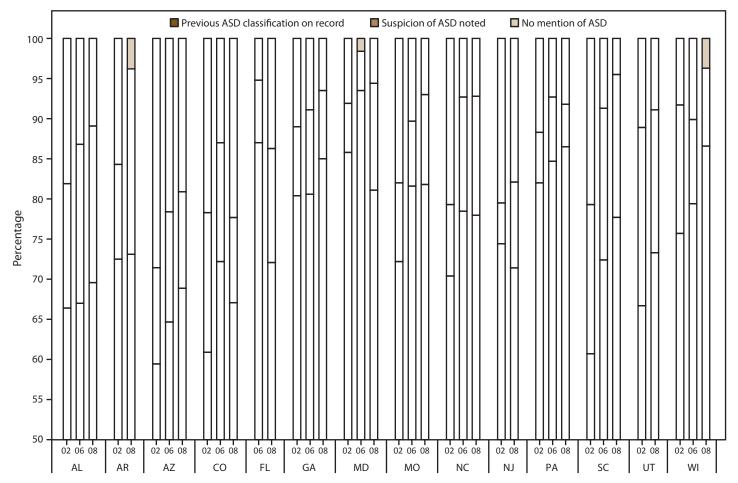
significantly higher prevalence of ASDs in 2008 compared with 2002 (Table 5). When data from all sites were combined, ASD prevalence estimates among children aged 8 years increased 78% during 2002–2008 (from 6.4 to 11.4 per 1,000). The combined increase across all sites was 82% for males (10.2–18.6 per 1,000) and 63% for females (2.4–4.0 per 1,000) during this 6-year period. The combined estimates indicated a 70% increase among non-Hispanic white children (7.0–11.9 per 1,000), a 91% increase among non-Hispanic black children (5.5–10.5 per 1,000), and a 110% increase among Hispanic children (3.7–7.7 per 1,000) during 2002–2008.

In the seven sites with IQ test data available on at least 70% of children with ASDs in both the 2002 and 2008 surveillance years, estimated prevalence of ASD with intellectual disability increased 45% on average (3.2–4.6 per 1,000), while the estimated prevalence of ASD with borderline intellectual

ability increased 117% (1.4–2.9 per 1,000), and the estimated prevalence of ASD with average or above-average intellectual ability increased 93% (2.4–4.7 per 1,000).

When data from all 13 sites participating in the 2002 and 2008 surveillance years were combined, the proportion of children meeting the ASD surveillance case definition who had a comprehensive evaluation completed by age 36 months increased over time, from 32% for children born in 1994 to 41% for children born in 2000 (i.e., children identified in the 2002 and 2008 surveillance years, respectively). During this time, the proportion with an earliest known ASD diagnosis by age 36 months increased from 12% for children born in 1994 to 18% for children born in 2000.

FIGURE 3. Proportion of children identified with autism spectrum disorders (ASDs) by previous ASD classification on record as of age 8 years, by state and year — Autism and Developmental Disabilities Monitoring Network, United States, 14 sites, 2002,\* 2006,† and 2008§



<sup>\*</sup> N = 2,682

<sup>&</sup>lt;sup>†</sup> N = 2,757

<sup>§</sup> N = 3,820

# Previously Documented ASD Classification: 2002, 2006, and 2008

The proportion of children meeting the ASD surveillance case definition who had a documented ASD classification in their records increased over time in seven of the 10 sites completing all 3 surveillance years (Figure 3). For these 10 ADDM sites combined, and restricting analysis to residents of the core surveillance areas that were common across all 3 surveillance years, the proportion of surveillance cases with a previous ASD classification increased from 72% in 2002 to 77% in 2006 and to 79% in 2008.

### Discussion

The results provided in this report suggest that three topics require further exploration. First, estimated ASD prevalence continues to rise in most ADDM Network sites, indicating an expanded need for programs serving children with ASDs. Second, a wide range of ASD prevalence was estimated across ADDM Network sites. Finally, estimated prevalence varied widely by sex and race/ethnicity. To address such wide variation in ASD prevalence estimates (over time, across sites, and between sex and racial/ethnic groups) a number of factors should be considered, primarily those focusing on ascertainment.

# **Temporal Changes in ASD Prevalence**

While ASD prevalence estimates in the overall population increased 23% for the 2-year period 2006-2008, and 78% during the 6-year period 2002–2008, the largest increases over time were noted among Hispanic children and non-Hispanic black children and among children without co-occurring intellectual disability. Better identification in these specific groups explains only part of the overall increase, however, as estimated ASD prevalence increased in all groups when data were stratified by sex, race/ethnicity, and intellectual ability. Previous reports from the ADDM Network have discussed underascertainment in racial and ethnic minority groups, and ADDM data have revealed ASD as one of the few developmental disabilities for which a positive correlation exists between socioeconomic status (SES) and identified prevalence of the condition (18). Further investigation is needed to better understand potential ascertainment bias and disparities by race/ethnicity and SES in access to diagnostic and treatment services for children with ASDs. If these gaps are decreasing, continued ASD prevalence increases might be expected overall and among specific groups.

Children meeting the surveillance case definition for ASD are not required to have an existing ASD diagnosis or classification on record, but examiners' diagnostic impressions do factor prominently in ascertainment methods and can influence temporal changes in ASD prevalence. Approximately 79% of all children meeting the surveillance case definition in 2008 had a documented ASD classification in their records, the highest proportion ever reported for any ADDM Network surveillance year. This offers evidence that providers in these communities are increasingly more likely to document the presence of ASDs and facilitate access to services that are specific to the needs of children with ASDs. Also, the proportion of children with an earliest known ASD diagnosis by age 36 months increased over time. However, 21% of the children meeting the ASD surveillance case definition do not have any documented ASD classification in their records, and those who do are not being identified early enough. In areas where autism-specific interventions are available to children who qualify on the basis of diagnosis, early screening and diagnosis improves access to services during the most critical developmental periods. Limitations in the data and report findings in terms of the earliest "known" diagnosis suggest that the diagnostic information obtained from evaluation records might not capture the exact age of each child's earliest diagnosis. Given this and the instability of diagnostic subtypes over time, the median age of earliest known diagnosis for any specific ASD should be interpreted cautiously. Nonetheless, the data indicate that many children with ASDs do not receive a diagnosis until they reach preschool or kindergarten age, missing opportunities for earlier therapies that potentially could improve communication and socialization while these skills are developing. Because the data for this report were collected on children born during 1994–2000, future reports from the ADDM Network might demonstrate greater progress in early identification stemming from policy changes initiated in recent years, including state-based insurance reform and the expansion of services for children with ASDs occurring in many states.

# Variation in ASD Prevalence by Site, Sex, and Race/Ethnicity

For the 2008 surveillance year, a wider range of site-specific ASD prevalence estimates was identified than in previous ADDM Network surveillance years. Variation in estimated ASD prevalence was associated primarily with sites having access to education records and also appeared to be associated with improved identification among children without intellectual disability. On average, estimated ASD prevalence was significantly higher in ADDM sites that had access to

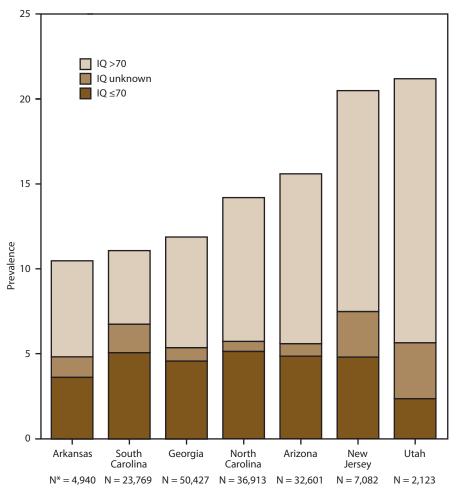
education sources compared with sites that relied solely on health sources to identify cases, and ASD prevalence in the one Colorado county where project staff had access to both health and education sources was almost twice as high as in the six counties where only health records were accessed. Such differences cannot be attributed solely to source access, as other factors (e.g., demographic differences and service availability) also might have influenced these findings. In general, however, having access to education records continues to be associated with higher identified ASD prevalence when comparing across or within most ADDM Network sites.

The two sites with the highest ASD prevalence estimates in 2008 (Utah and New Jersey) identified higher proportions of children with IQ >70 compared with any site participating in 2008 or previous ADDM Network surveillance years. Among the seven sites reporting data on intellectual ability, ASD prevalence was typically higher in sites having a greater percentage of children with IQ >70 (Figure 4). Because testing practices and other factors that influence these findings might vary across sites, further analysis is needed to understand this pattern in 2008 and earlier ADDM surveillance years.

The availability of children's records also was identified as a potential source of underascertainment and variation in ASD prevalence estimates among sites. When a sensitivity evaluation algorithm was applied to counts of records that could not be located

for review, estimated ASD prevalence in some sites might have been much higher if all children's records had been available for review. In other sites, however, the impact of missing records was considered negligible, so record availability likely accounted for at least some of the variation across sites. Because nearly half of the missing records in Florida were from a program serving children aged birth to 3 years, 26% is considered a liberal estimate, and the actual yield from these early childhood records might have been smaller. In Alabama, the vast majority of missing records was from facilities that were in the process of converting from paper to electronic records or had storage limitations during the period of data collection, so the large number of missing records might have had a one-time effect on the 2008 surveillance data for this site.

FIGURE 4. Variation in estimated prevalence (per 1,000 population) of autism spectrum disorders (ASDs) among children aged 8 years, by Intelligence Quotient (IQ) score — Autism and Developmental Disabilities Monitoring Network, seven sites,\* United States, 2008



<sup>\*</sup> Includes sites having information on IQ score available for at least 70% of children who met the ASD case definition.

The estimated prevalence of ASDs was significantly higher among boys (one in 54) than among girls (one in 252), with a male-to-female RR of 4.6 for all sites combined. Although the ADDM site with the highest ASD prevalence had the lowest male-to-female ratio while the site with the lowest ASD prevalence had the highest male-to-female ratio, improved identification among females compared with males did not appear to be associated with between-site differences in overall ASD prevalence. Much wider variation existed in sites' prevalence estimates for males than for females.

ASD prevalence estimates also varied widely by race/ethnicity across and within most sites, with only one site (New Jersey) identifying approximately the same ASD prevalence among non-Hispanic white, non-Hispanic black, and Hispanic children. Most ADDM Network sites continue to identify

<sup>&</sup>lt;sup>†</sup> Total population aged 8 years.

higher ASD prevalence estimates among non-Hispanic white children compared with other racial/ethnic groups, and with no clearly documented differences between these groups in known risk factors for ASDs, disparities in prevalence estimates suggest underascertainment among Hispanic and non-Hispanic black children. However, these disparities in identification appear to be diminishing in many sites, and further work is needed to evaluate how identification among certain racial/ethnic populations is associated with differences in ASD prevalence between sites and over time.

#### Limitations

The data provided in this report are subject to at least two limitations. First, increases in awareness and access to services have improved the ability of the ADDM Network to identify children with ASD over time, and this likely contributes to the increase in estimated prevalence. The proportion of the increase that is attributable to such changes in case ascertainment or attributable to a true increase in prevalence of ASD symptoms cannot be determined. Ongoing monitoring is an important tool to learn why more children are being identified with ASDs and can provide important clues in the search for risk factors.

Second, the surveillance areas were not selected to be representative of the United States as a whole, nor were they selected to be representative of the states in which they are located. Limitations regarding population size, surveillance areas, and the consistency of these attributes were considered when analysts evaluated comparisons across multiple time points. Although the two ADDM sites reporting the highest prevalence estimates in 2008 also reported among the highest prevalence estimates in 2002, the most recent results from New Jersey and Utah are based on subregions of their 2002 surveillance areas, with smaller populations compared with those areas and with most other ADDM sites. The estimated prevalence in these subregions possibly was influenced by factors unique to these smaller communities and might not reflect the number and characteristics of children with ASDs in the larger areas covered by these ADDM sites in 2002. Similarly, five other ADDM sites covered different surveillance areas in 2008 compared with 2002 and/or 2006. Although comparisons with earlier surveillance years were carefully restricted to comparable surveillance areas, caution is advised when interpreting results. For example, the addition of one North Carolina county in 2008 resulted in a nearly 15% increase in the overall prevalence of ASDs in that site compared with their findings when this new county was excluded from the prevalence estimate. Although this county was excluded from calculations when the 2008 results were compared with those from earlier surveillance years, the impact of this single county highlights the relative differences across subregions of any given ADDM site.

# **Future Analyses to Address Limitations**

For differences in ASD prevalence, across sites and within subregions of each site to be understood better, further exploration of geographic variation in multiple contextual and potential risk factors is needed. This involves in-depth analysis of known characteristics in the population of children identified with ASDs (e.g., intellectual ability, SES, and birth characteristics), as well as geographic differences affecting the population as a whole. These results point to a need for geospatial analyses of both physical and social environments, including occupational and socioeconomic characteristics of the population, state policy differences potentially affecting access to services (e.g., insurance reform, per capita educational spending, and immigration policy), and geographic differences in environmental exposures that potentially might affect neurodevelopment.

Another important consideration for future analyses is the changing clinical definition of ASDs over time. Although the ADDM methods have always been based on the DSM-IV-TR (1) diagnostic criteria, proposed changes to the definition of Autism Spectrum Disorder in the forthcoming revised Diagnostic and Statistical Manual of Mental Disorders (DSM-5) might affect prevalence estimates and complicate temporal comparisons (19). The proposed revised diagnostic criteria for Autism Spectrum Disorder would combine three subgroups currently under the DSM-IV-TR heading of Pervasive Developmental Disorders into one category and might require a child to display more pronounced symptoms to receive a diagnosis. Because the ADDM methods include information on a broad range of symptoms, the ADDM Network is well-positioned to adopt the proposed DSM-5 definition into its ongoing study and, at the same time, obtain comparison estimates based on the DSM-IV-TR definition. CDC and ADDM Network investigators are exploring the data to understand how the proposed changes might affect the current prevalence estimates and will continue to prioritize these comparisons so as to understand trends better over time. This information is crucial to increasing knowledge of this complex spectrum of behaviors.

# **Ongoing Efforts**

Although multiple factors influence the identification of children with ASDs and differences in prevalence estimates across sites, the data provided in this report indicate the need for further exploration of possible associations between overall ASD prevalence and improved identification among children without

intellectual disability, children in all racial/ethnic populations, and both males and females, including potential interactions between these factors. ADDM Network investigators continue to explore a broad variety of potential risk and ascertainment factors to understand differences in ASD prevalence estimates between sites and over time.

With 5 surveillance years completed to date, and data collection underway for the 2010 surveillance year, the ADDM Network has compiled extensive data on the prevalence and characteristics of ASDs and other developmental disabilities. These data cover large populations for obtaining prevalence estimates and provide depth and breadth of information on topics not captured in national health surveys. The ADDM record-review methodology enables reporting of data on intellectual ability, specific ASD subtype diagnosis and educational classification, within- and between-state comparisons, and linkage to other datasets for exploration of potential risk factors such as birth characteristics and socioeconomic disparities as well as examination of health services utilization. Currently, the ADDM Network is collecting information on children who were aged 8 years in 2010 and for the first time also is monitoring ASDs among children aged 4 years. In 2012, ADDM sites will begin collecting information for the 2012 surveillance year.

### Conclusion

ASDs continue to be an important public health concern. The findings provided in this report confirm that prevalence estimates of ASD continue to increase in the majority of ADDM Network communities, and ongoing public health surveillance is needed to quantify and understand these changes over time. Further work is needed to evaluate multiple factors affecting ASD prevalence over time. ADDM Network investigators continue to explore these factors in multiple ways, with a focus on understanding disparities in the identification of ASDs among certain subgroups and evaluating temporal changes in the prevalence of ASDs. CDC also is engaged with other federal, state, and private partners in a coordinated response to identify risk factors for ASDs and meet the needs of persons with ASDs and their families. Additional information is available at http://www.cdc.gov/autism.

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